

## Sibling Relationships and Developmental Disability Services: From Coerced Care to Entitlement



### What this research is about

Social service policies often neglect the right of people with intellectual/developmental disabilities (ID) to exercise agency and shape their own lives. Early policies portrayed people with ID as posing financial and social burdens on their families. It was expected that family members would step into caregiving roles, or what the researchers of this study define as “coerced care,” given the lack of choice for both the person who gives and the person who receives care. This expectation is still prevalent in society today. Family members who shoulder the caregiving roles are often women.

This study examines existing research and survey data to understand how unpaid care work by family members of people with ID in Ontario is influenced by an underfunded developmental services system and gendered social norms.

### What the researchers did

Using both existing research and survey data, the researchers looked at how unpaid care work for people with ID is organized in Ontario. This body of research is analyzed and interpreted through a feminist lens, with a specific focus on the role of siblings, especially sisters. The researchers examined how current care practices often undervalue people with ID and limit their ability to choose who supports them.

### What the researchers found

Positioning people with ID as “problems” that society has to deal with shifts the blame and responsibility to their mothers, who are seen as the source of the problem. This practice of “mother-blaming” helps create and reinforce gendered social norms that expect women to provide unpaid care for their family

### What you need to know

This research explores how financial reforms along with budget cuts in Ontario’s developmental services system have placed increased pressure on families of people with intellectual and developmental disabilities (ID). It critically examines how unpaid care work is shaped by systemic underfunding, social devaluation of disabled people, and a lack of choice in care arrangements. Drawing on existing research and survey data, the researchers highlight the risks of what they term “coerced care” and analyze the historical expectation that women will assume lifelong unpaid caregiving roles. Siblings, particularly sisters, are expected to take over unpaid care roles from their parents. The lack of choice for people with ID regarding who cares for them as well as where and with whom they live can significantly decrease their autonomy and quality of life.

member with ID. This care work is rarely recognized or appreciated in social or economic terms.

While disability rights movements have helped push for the recognition of disabled people’s rights, the impact at the policy and program level has not been realized. As a result, the responsibility of care still often falls on families. With few paid support options available, people with ID often end up depending on care from family members, usually mothers and sisters, who may feel pressured to take on the caregiving role. The limited options mean that people with ID may have little say in who provides care to them. This can have negative effects on their autonomy and quality of life, especially if their caretaker does not share their values. Families of

people with ID often find themselves becoming advocates. However, differences in values and opinions on sensitive subjects like reproductive rights can cause family-led advocacy initiatives to clash with self-advocacy led by people with ID.

Research has shown that siblings often anticipate taking over care for their sibling with ID as their parent(s) age. Sibling caregiving is strongly shaped by gendered norms, with sisters more often expected to take on this role from their mothers. According to a study, while many siblings said they were comfortable with that role, some also indicated they were not prepared financially or emotionally. While brothers are less likely to be involved, they are more likely to help if their sibling is also male. Studies have also shown that caregivers are usually older and have a close relationship with their sibling with ID. They are also more likely to be single, have lower levels of education and income, and rely on public benefits.

Research in Canada shows that women who care for people with ID face high risks of poverty, poor health, and other social challenges. These risks are even greater when these women are unpaid and live in the same home as the person they are supporting. Losing paid work is a major concern, often leading to long-term financial and health problems. One study found that women in a caregiving role are especially likely to leave their paid job so they can continue providing care. A report from the Ombudsman of Ontario confirms that adults with ID face significant risks when their primary unpaid caregiver is no longer able to provide essential support. According to the report, this loss of care can quickly lead to crisis situations. These may include abandonment, abuse, homelessness, or even death—particularly when stable, consistent, and dependable supports are not in place.

### How you can use this research

Tailored supports for people with ID that meet their needs and are independent of changing government priorities could be created. The researchers suggest an entitlement-based approach to ensure tailored supports and services for people with ID, based upon the United Nations Convention on the Rights of

Persons with Disabilities. Decision-making and policy design for these services are as important as budgetary concerns to ensure people with ID have a choice when it comes to who their caregivers are as well as where and with whom they live.

### About the researchers

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*Research Snapshot by Erika Cao*

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The Vanier Institute of the Family has partnered with the Knowledge Mobilization Unit at York University to produce Research Snapshots.

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